

European Challenges: Cross-Border Care for Children

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Europe has seen a 60-year era of postwar peace, wealth, social justice, and ecological awareness. This prosperity and resultant improved health has not been experienced equitably across all population groups, however. Indeed, inequalities within and between nations have increased over this time, and that trend shows no sign of changing. The banking crisis and the entry into a period of austerity are likely to accelerate the trends toward greater inequities. Children and young people will be particularly adversely affected as poverty, unemployment, reduced benefits, and cuts in public services are experienced. The unemployment rates among young people have already reached alarming levels in the countries most burdened by excessive national debt. An examination of life course epidemiology suggests that future investments should be made in childhood to prevent morbidity in adulthood, but the demographic shift toward the elderly population as individuals live longer is creating demands on health services that are outstripping the available resources. This will eventually precipitate a debate on where resources are best invested. The answer to this question will depend not only on good evidence and econometric studies, but also on cultural values and attitudes about social solidarity.

Currently there are considerable variations in the access to, and quality of, specialized pediatric services across Europe, with the starkest difference between Eastern European and Western European nations. This is leading to increased numbers of families seeking highly specialized care in countries outside their own. Despite an awareness of the problem by the European Union (EU) member states, how national governments should best respond to complex issues regarding cross-border healthcare remains unclear.¹ There is also a lack of Euregios offering cooperative healthcare in regions of neighboring countries.²

There is a paucity of demographic data on pediatric cross-border health care in Europe. The aim of the European Paediatric Association is to analyze the current situation to provide the necessary evidence to improve future priority setting and decision making. This will require a degree of cooperation, collaboration, and coherence of an approach on a pan-European basis if we are to understand how different health systems create the outcomes that they achieve for their children and young people. The European Paediatric Association has identified the need for professional pediatric socie-

ties to establish best practice clinical pathways, standards, and measures for cross-border pediatric care.

This report provides a review on concerns and options around cross-border pediatric care based on the findings of the “Bridges for Combating Health Inequalities in Life-Threatening Diseases (CHILD)” conference held on November 17-18, 2011, in Vienna, Austria, supported by a EU grant provided by the Executive Agency for Health and Consumers within the frame of the second Health Program (agreement no. 2010 42 04; www.bridgesforchild.eu). The purpose of the conference was to examine the options for improving current practice and policy of cross-border care in Europe for children requiring specialist care for life-threatening diseases of the heart, lungs, liver, and kidneys.

Europe is divided into 46 countries (plus 7 small states, including the Vatican and Monaco), with a total of 184 border regions with large populations. Two islands of the 46 countries have no border region, 37 countries have between 1 and 6 border regions, and 7 countries having 7 or 8 (mode: 4). Seven of the 46 countries have fewer than 2 million inhabitants and another 7 countries have a population of 2-4 million. Therefore, one-quarter of European countries may be too small to offer highly specialized health care within their national health systems to their small number of children with rare and complex diseases. Thus, for example, in countries like Macedonia, all children needing open-heart interventions for congenital heart malformations are sent to Sofia, Bulgaria, for surgery.

The borders are not only geographical, but also cultural where healthcare systems interface. Understanding the diversity of child healthcare means that each individual and nation is unique and recognizes and works with these individual and national differences. These can be along the dimensions of ethnicity, culture, socioeconomic status, religious beliefs, political beliefs, and other ideologies. These differences and their influences on cross-border care should be explored in a safe, positive, and nurturing environment. The conference site of Vienna was chosen to host Bridges for CHILD because the Medical University of Vienna is located in the center of Europe, where east, west, north, and south naturally meet. Eighty-eight participants, including pediatric subspecialists

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Table I. Arguments for and against developing a more rational system on European cross-border transplant care for children

Arguments for a more rational system

- Children have the right to high-quality health care regardless of cultural background or ability to pay (article 24, United Nations Convention on the Rights of the Child).
- The current system is not efficient, effective, or equitable, and, in times of economic austerity, there is a greater moral obligation to use limited resources wisely.
- Increasing the number of children accessing specialist centers potentially improves the quality of care provided in those centers as their confidence improves with increasing numbers.
- Addressing the issue of the threshold for accessing specialist care should improve decision making along the whole pathway of care. This has the potential to improve the quality of primary and secondary care as well.
- The purpose of the EU and of the Council of Europe is to create social solidarity based on human rights, democracy, and the rule of law.

Arguments against a more rational system

- Specialist care, especially interventional specialist care, such as transplantation, is expensive. This may be unaffordable for resource-poor nations.
- The opportunity costs for others may be unacceptable for the society (eg, 1000€ could save more lives if spent in different ways).
- Posttransplantation services are unlikely to be available in resource-poor nations.
- A higher priority in many nations is the development of effective and responsive palliative care services.
- There seems to have been a lack of political willingness to tackle this difficult issue in the past, the argument being that each nation should resolve its own problems without taking a pan-European approach.

from 20 European countries, as well as parents of sick children, health insurance experts, politicians, representatives of nongovernmental organizations, and medical students, attended the conference. The 2-day conference included invited lectures and 9 round-table sessions. The individual commitment of all participants and the multidisciplinary lineup, combined with the roundtable format, contributed to the conference's success.

Many European children with severe conditions are not receiving high-quality care; therefore, their experience and outcomes of services are poor. Poor-quality care generally costs more in the long term, and the current system is ineffective, inefficient, or inequitable in many countries. This is particularly true for children living in resource-poor nations, generally those toward the east of Europe, which have less-developed services. The problem is compounded by the difficulties in accessing cross-border care, which include social, political, and financial dimensions. From the perspective of the European pediatric specialist centers in the better-

developed nations, they are receiving multiple requests every week, often without adequate information to enable appropriate decision making, which reflects the quality of care in the country of origin. If one request for specialist care is turned down, further requests to other specialist centers are made, and the whole process is hugely time-consuming and inefficient. Arguments for and against Europe-wide structured cross-border care are listed in [Table I](#). Additional factors involved are described in [Table II](#).

The intention of Bridges for CHILD is to create a system that improves quality throughout each child's pathway from prevention through identification/recognition and comprehensive assessment of both child and family to improve access to a range of effective interventions, including specialist care for both severe and rare conditions. Although the focus of the conference was on high-tech surgery and transplantation for life-threatening conditions, many recognized that the quality of care throughout the child's life was equally important and could significantly delay the need for

Table II. Additional factors that need to be considered

- Access to specialist care must not be seen in isolation from the care the child received before and after access to specialist care. Thus, improving the quality of care before and after specialist interventions is an equal priority.
- Current systems for accessing specialist care are often highly bureaucratic, time-consuming, and illogical and do not facilitate "the right care, for the right child, by the right people, in the right place, at the right time."
- Access to specialist care in Europe needs to be seen as a "whole systems" issue. Changing whole systems requires agreement among all of the stakeholders, including users of services, their political representatives, financial systems (whether public, insurance-based, or private), health professionals, and other agencies that contribute.
- In all social systems, there is an element of financial risk pooling meaning everyone contributes a little to benefit should an individual catastrophe occur. The question is how far the borders should be stretched for risk pooling for health conditions: regional, national, or international?
- The EU offers subsidies to farmers and other industries, but generally not within healthcare.
- The development of specialist centers within Europe needs to be limited so that the current centers have sufficient capacity to maintain and expand their competence.
- Many specialist services are codependent on one another, and, thus, decisions made for one specialist service must be seen in the context of developments for interrelated specialist services. This may require a rationalization of the location of specialist services across Europe.
- Horizon scanning. As medicine and technology improve, current interventions may be substituted with less-invasive future procedures. Developments in stem cell technology, gene therapy, and nanotechnologies need to be considered so that decisions taken today are compatible with the likely future developments.
- Payment methods for specialist care should be reviewed to adequately remunerate specialist centers undertaking the work. Often children with rare conditions have multiple comorbidities that influence the interventions and outcomes required. Children from other countries require translating services, and their families often need help with transportation and accommodation costs. Care for other children in the family also needs to be considered.
- Improving the quality of care for children requiring specialist care also requires improved transparency about what centers offer what services and the quality and outcomes that they achieve.

Table III. Urgent actions envisaged during the roundtable sessions of “Bridges for CHILD”

<p>How to treat children with congenital heart disease under adverse economic conditions?</p> <ul style="list-style-type: none"> • A patient database in the Pediatric Cardiac Center of Prishtina University, Republic of Kosovo, will be set up. • An educational twinning project on decision making in CHILD scenarios between Prishtina University and Vienna University will be established before the end of 2012. <p>How to achieve accountability in new cardiology centers?</p> <ul style="list-style-type: none"> • Parents' desire for cross-border training of local cardiac experts and for further public support of the European Congenital Heart Disease Organization will be reported to the Association of European Paediatric and Congenital Cardiology. • National parents' organizations will stimulate medical associations in their countries to establish basic guidelines for standard treatment of children with congenital heart disease and other life-threatening diseases. <p>What is needed to ensure optimal care of children and adolescents before and after cross-border lung transplantation?</p> <ul style="list-style-type: none"> • The Vienna lung transplant center will invite insurance and health care authorities of Eastern European countries to a meeting, and it will also apply for grants from the European Respiratory Society and the Cystic Fibrosis Foundation. • The issue of cross-border lung transplantation will be included into the programs and agendas of future national meetings in Hungary and Austria. <p>How to organize care pathways in solid organ/stem cell transplantation?</p> <ul style="list-style-type: none"> • A team will be put together to define the relevant variables for analysis of the current status and, thereafter, to identify specialists who could become members of a Pediatric Cross-Border Transplant Task Force. • A task force on cross border pathways for children with life-threatening kidney diseases will be proposed to the European Society for Paediatric Nephrology. <p>What can universities contribute to the reduction of health care inequalities in European child healthcare?</p> <ul style="list-style-type: none"> • A task force for a telemedicine model on decision making in CHILD scenarios will be set up. <p>How to structure care pathways for life-threatening/life-limiting diseases in local and cross-border health care?</p> <ul style="list-style-type: none"> • The potential will be explored for a single clearing house for requests for solid organ transplants and advocates developing standards for centers providing solid organ transplants. <p>How to transform the directive on patients' rights in cross-border health care into reality: economic gradients, medical indications, and codes of conduct?</p> <ul style="list-style-type: none"> • Those medical establishments involved in cross-border pediatric tertiary care should set up guidelines for acceptance and nonacceptance of patients from other countries.
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organ replacement therapy if all of the decisions had been made at the right time. There will be a spectrum of options, but 4 options were presented as a starting point: (1) current trajectory, increasing the numbers of children “randomly” receiving specialist care as public awareness of the options available become more widely known; (2) partnership programs, with large specialized centers in Europe “partnering” with less well-resourced nations to provide education and training, outreach services, and specialist interventions and after care determined by respective governments/insurance/health systems; (3) clearing house, with requests for specialist care considered by a panel of experts who collectively decide on a pan-European basis whether the child can benefit from specialist care and determine to which center the child is referred; and (4) designated centers, with a limited number of comprehensive centers of excellence designated and funded by the EU to undertake specific interventions for children meeting agreed-upon criteria.

In summary, the participants of the CHILD conference agreed that European pediatricians should analyze and describe the present situation, and several proposals for

new initiatives were made (**Table III**). The CHILD Task Force members will be expected to present results at the proposed second Bridges for CHILD conference to be held in 2014 in Vienna. Clinicians should initiate the process of reforming health services for children and families, and should start the process by being open about where the systems are not working and the reasons for these deficiencies, and reaching consensus within pediatric subspecialty services. In the longer term, to be politically credible and sustainable, pediatricians need to form alliances with patient organizations, health service managers, and the organizations that plan and finance services. ■

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